

# Your role as a carer



Looking after your physical and mental health is important, so be sure to make this a priority.

## Caring for yourself

Caring for someone with a life-limiting illness can be both rewarding and challenging. On top of that role, you may have family or work commitments. It is important to find ways to balance your caring role and other responsibilities, so that you maintain a sense of wellbeing.

Looking after your physical and mental health is important, so be sure to make this a priority.

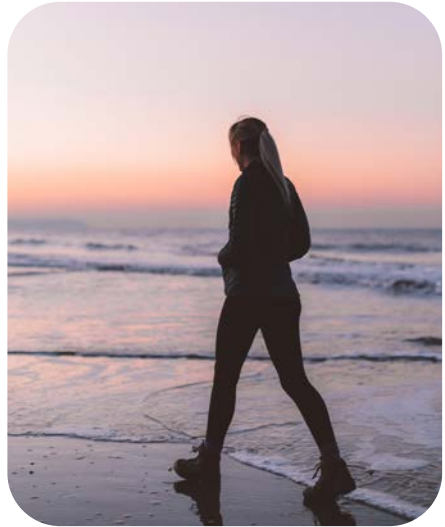
There is no need to feel guilty about caring for you. Many people receiving care feel better if they know their carers are taking time to enjoy themselves and rest.

### Get some exercise

Doing something physical will help you remain fit and well and maintain your energy. Try an exercise that you enjoy and can fit easily into your routine. Walking, swimming and daily stretching are good examples.

### Get enough sleep

Lack of sleep can become a problem for carers as the person they care for becomes increasingly unwell. Often stress and a busy mind can keep you awake. Limit coffee and alcohol intake, especially in the latter part of the day. Try relaxing with a warm bath or herbal tea before bedtime.



Sometimes listening to soothing music or reading a book can help you unwind. If you find sleeping difficult on a regular basis, see your nurse or doctor. Importantly, try to avoid driving or making important decisions if you are overtired.

### Maintain a healthy diet

Try to maintain a well-balanced diet and stay hydrated. Factors such as stress or a disrupted routine may affect your appetite. If your appetite decreases and becomes a matter of concern, seek advice from your doctor.

### **Be social**

Try to maintain social contact with friends, other family members and usual social groups. Keep up your usual activities as much as possible.

### **Practise your own spirituality or religion**

Whether it be meditation, yoga, prayer or discussion with a pastoral worker, maintaining religious or spiritual practice will help you to stay well.

### **Do something for yourself every day**

Consider activities to help clear your mind such as walking, gardening, meditation or listening to music. Take a break – list the things you enjoy that would give you a short break and renew your energy. Do one of these things each day, for example, take time out for a sport, craft or artistic activity.

## **Tuning in to feelings and emotions**

It is normal for carers to experience a range of feelings and emotions, including fear and resentment. You may fear the unknown, or worry you won't be present when the person you are caring for dies.

There are also times when you will see the funny side of things. It's okay to maintain a sense of humour and enjoy a good laugh along the way.

Being aware of your feelings and emotions will help you to cope with the grief, anxiety and sadness that are a natural part of being with someone as they approach the end of life. Recognise your physical and emotional limits.

It is okay to stop being a carer. Even though you may have promised the person who is unwell that you would always look after them, it may not be possible. You may feel distress or guilt at having to say that you are unable to continue. You may find it hard to hand over to someone else. You may also feel a sense of relief. This is ok as well. There is no right or wrong way to feel about giving up this role.

You may find you still want to be involved but in a lesser way.

## Asking for help and accepting it

Sometimes carers find it hard to acknowledge that they need help, fearing it is a sign of weakness or that they are not coping.

Often carers do not seek help for themselves because they consider their needs less important than those of the person they are caring for.

Do not be afraid to ask for help. Your wellbeing is vital to your role as a carer. Try to share the load so you don't become overwhelmed and exhausted.

Providing Palliative Care at home is a big commitment which requires the help of family, friends and others close to the person who is unwell. Often family and friends would like to help but are unsure what to do. Practical assistance like making a meal, walking the dog, buying groceries and hanging out the washing can make a big difference to your load.

Consider:

- Making a list of family and friends who could provide practical support. Invite them to choose from a list of tasks so you can lessen your workload. For example, mowing the lawn, taking out rubbish, providing meals or transport and so on.

- Asking a friend or family member to stay overnight, so you can get a good night's sleep.
- Setting up a roster if more than one person is providing care.
- Finding out what local services or community groups provide volunteers or support programs.
- Making contact with your local Palliative Care service to discuss what help is available and how to access it.



## Communicating effectively

It is normal for your relationship with the person you are caring for to have ups and downs. The stress of coming to terms with a life-limiting illness, the impact this has on family members, and the physical and mental exhaustion of caring for someone can all take a toll. Your relationship may at times feel strained, or stronger than ever. While caring for someone, it is important to keep communicating, even though talking to them about their illness and dying may be difficult.

It will be useful to have regular conversations with family members so they know what is happening and what to expect as the illness progresses. Sometimes strong opinions about important care decisions can lead to conflict. You might find this distressing, particularly if someone not directly involved in day-to-day care offers unsolicited advice or direction.

It is important for family members to recognise that the person with a life-limiting illness has the right to make decisions about all aspects of their treatment and end-of-life care if they have the capacity to do so.

If communication becomes a problem, consider asking a skilled professional to facilitate a family meeting where all members can share their concerns, problem solve and provide support.

## Involving children

Children and young people often manage stressful situations better if they are told the truth in a way that reflects their level of understanding. They can become distressed if they see adults upset and are not given an honest explanation of what is happening, or their questions are dismissed. Encourage them to ask questions and provide reassurance.

Give children choices about how to interact with them, whether that is face-to-face, drawing pictures, making cards or sending photos, messages or letters.

Try to maintain routines as much as possible and offer children the chance to help with caring.


## Managing visitors

You may need to manage visiting times so that you and the person you are caring for have ample time to rest and attend to other tasks as necessary. Sometimes well-meaning visitors stay too long.

Before visitors arrive, suggest a reasonable period of time for their stay. As the time to leave approaches, remind them if necessary.

You might want to prepare the visitors on the state or the appearance of the person they are visiting as they may look quite different.

You might also suggest the best time for visitors to come. For instance, a late morning visit will allow time for an early afternoon rest. A nicely worded sign near the doorbell stating convenient visiting times might also help to minimise poorly-timed impromptu visits. It may become necessary to set up a roster to limit visiting times.





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## Useful contacts



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### Australian Indigenous Health InfoNet

-  (08) 9370 6336
-  [healthinonet.ecu.edu.au/learn/health-system/palliative-care](https://healthinonet.ecu.edu.au/learn/health-system/palliative-care)



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### Cancer Council NSW

-  13 11 20
-  [cancercouncil.com.au](https://cancercouncil.com.au)



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### Carer Gateway

-  1800 422 737
-  [carergateway.gov.au](https://carergateway.gov.au)



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### Carers NSW

-  (02) 9280 4744
-  [carersnsw.org.au](https://carersnsw.org.au)



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### Caresearch

-  (08) 7221 8233
-  [caresearch.com.au](https://caresearch.com.au)



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### Centrelink

-  13 27 17
-  [servicesaustralia.gov.au](https://servicesaustralia.gov.au)



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### Dementia Australia NSW

-  1800 100 500
-  [dementia.org.au](https://dementia.org.au)




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### GriefLine National

-  1300 845 745
-  [griefline.org.au](https://griefline.org.au)

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### Leukaemia Foundation

-  1800 620 420
-  [info@leukaemia.org.au](mailto:info@leukaemia.org.au)
-  [leukaemia.org.au](https://leukaemia.org.au)



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### Lifeline

-  13 11 14
-  [lifeline.org.au](https://lifeline.org.au)

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### My Aged Care

-  1800 200 422
  -  [myagedcare.gov.au](https://myagedcare.gov.au)
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### My Health Record

- 📞 1800 723 471
- 🖱️ [myhealthrecord.gov.au](https://myhealthrecord.gov.au)

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### National Disability Insurance Service (NDIS)

- 📞 1800 800 110
- 🖱️ [ndis.gov.au](https://ndis.gov.au)

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### National Stroke Foundation

- 📞 StrokeLine: 1800 787 653
- 🖱️ [strokefoundation.org.au](https://strokefoundation.org.au)

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### NSW Trustee & Guardian

- 📞 1300 109 290
- 🖱️ [tag.nsw.gov.au](https://tag.nsw.gov.au)

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### Palliative Care NSW

- 📞 (02) 8076 5600
- 🖱️ [palliativecarensw.org.au](https://palliativecarensw.org.au)

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### Relationships Australia

- 📞 1300 364 277
- 🖱️ [relationships.org.au](https://relationships.org.au)

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### Services Australia

- 📞 [servicesaustralia.gov.au/individuals/contact-us/phone-us](https://servicesaustralia.gov.au/individuals/contact-us/phone-us)
- 🖱️ [servicesaustralia.gov.au](https://servicesaustralia.gov.au)

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### The Department of Veteran's Affairs

- 📞 General enquiries: 1800 838 372
- 📞 Counselling Service: 1800 011 046
- 🖱️ [dva.gov.au](https://dva.gov.au)

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### If you require an interpreter, contact the Translating and Interpreting Service (TIS National)

- 📞 13 14 50
- 🖱️ [tisnational.gov.au](https://tisnational.gov.au)

### If you have a hearing or speech impairment, contact the National Relay Service

- 📞 24 hour relay call numbers  
TTY/voice calls: 133 677  
Speak and Listen: 1300 555 727  
SMS Relay: 0423 677 767
- 🖱️ [relayservice.gov.au](https://relayservice.gov.au)



Caring for someone as they approach the end of their life can be both rewarding and demanding. It is hoped that this book will help to explain what caring involves, so you are better equipped to make informed decisions which reflect your needs and circumstances.

**You matter.**



**Palliative Care**  
NEW SOUTH WALES

**Palliative Care NSW**

706/50 Clarence St Sydney NSW 2000

(02) 8076 5600

[info@palliativecarensw.org.au](mailto:info@palliativecarensw.org.au)

[palliativecarensw.org.au](http://palliativecarensw.org.au)